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Stress, time pressure, and decision making

Lindsey Michelle Schutte

Washington University School of Medicine in St. Louis

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**STRESS, TIME PRESSURE, AND DECISION
MAKING**

by

Lindsey Michelle Schutte

**An Independent Study
submitted in partial fulfillment of the
requirements for the degree of:**

Master of Science in Deaf Education

**Washington University School of Medicine
Program in Audiology and Communication Sciences**

May 18, 2012

Approved by:

**Christine Clark, M.A. Ed., Independent Study Advisor
Karen Stein, M.A. Ed., Secondary Reader**

Abstract: This study surveys parents with children who are deaf or hard of hearing from one private school in St. Louis, Missouri. The issue of stress and time pressure on decision making is addressed and the importance of how stress and time pressure effect parents' decisions regarding their children who are deaf and hard of hearing.

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Abbreviations

1. The Joint Committee on Infant Hearing (JCIH)
2. Universal Newborn Hearing Screening (UNHS)

Introduction

The birth of a baby into a family brings with it many changes and challenges. Research has shown that all parents experience stress, and parents with children who have hearing loss exhibit even more stress (Quittner, Steck, & Rouiller, 1991). Parents are obligated to face many unfamiliar challenges, while managing a disability such as hearing impairment, early in the child's life without any emotional preparation. This may cause parents to feel pressured into making highly stressful, yet crucial decisions about amplification and education very early in the child's life. Often during these decisions, time pressures are put on the parents without any guarantees of future outcomes. It is important that audiologists, early interventionists, medical professionals, and other professionals are aware of the repercussions of parental stress and how this stress can affect their choices on very important decisions.

Background

Stress and Decision Making

Decision making is a complex cognitive activity. It is sensitive to situational and environmental conditions. Psychological stress is a known factor that significantly impacts decision making. It is argued that cognitive functioning and decision-making processes deteriorate under stress (Zakay, 1993).

Mandler (1982) found that when people are under stress the range of alternatives available to them and the dimensions of each of those decisions that are considered during the decision making process are significantly restricted, as compared with normal conditions. Research suggests that an individual under stress devotes part of their conscious attentional capacity to the stress and therefore is left with insufficient capacity to deal with the decision. This could result in the incomplete consideration of alternatives which is a defense mechanism to

prevent information overload. Disorganized and incomplete scanning of alternatives to a decision might result in an escape from an undesirable situation as quickly as possible (Mandler, 1982).

Another study suggested that stress might impair essential cognitive abilities that are at the core of the decision making process. Cognitive flexibility, reasoning, the ability to distinguish between important and useless information, planning ability, concentration, and the ability to retrieve from memory were found to be impaired under stress (Hamilton, 1982).

Janis and Mann (1976) developed coping patterns for decision making under stress. The coping patterns are determined by the presence or absence of three conditions: awareness of serious risks for whichever alternative is chosen, hope of finding a better alternative, and belief that there is adequate time to search and deliberate before a decision is required. The five coping patterns identified are unconflicted adherence, unconflicted change, defensive avoidance, hypervigilance, and vigilance (Janis & Mann, 1976).

In unconflicted adherence the decision-maker decides to continue whatever he or she has been doing, ignoring the information about the risk. In unconflicted change, the decision maker adopts whichever new course of action is most striking or most strongly recommended to them by others without thinking. In the defensive avoidance coping pattern, the decision-maker avoids the conflict by procrastinating, shifting responsibility to someone else, or by creating wishful rationalizations and remaining inattentive to corrective information. In hypervigilance, the decision-maker searches anxiously for a way out of the dilemma and grasps onto a fast solution that seems to promise immediate relief, overlooking the full range of consequences because of emotional excitement and repetitive thinking. Panic is hypervigilance in its most extreme form. Vigilance is evident when the decision-maker searches carefully for important information, understands the information in a neutral manner and evaluates the alternatives carefully before

making a choice. Vigilance allows stable and balanced decision making. The intensity of the stress is related to the coping pattern utilized: low stress and intense stress are likely to cause defective patterns of decision making (unconflicted adherence, unconflicted change, defensive avoidance, and hypervigilance) while intermediate levels are more likely to be associated with vigilant information processing (Janis & Mann, 1976).

Time Pressure and Decision Making

An important environmental factor that increases the feeling of psychological stress is time. Time pressure is common in many settings, especially in situations in which important and complex decisions must be reached in a timely manner.

George (1974) states that making a decision is a stressful condition, and managing the lack of knowledge about choices or the inability to process all available information causes emotional stress. Time pressure may increase this stress because parents feel a strong sense of failure when they can't process this critical information. Time pressure may also induce feelings of helplessness since fast processing is required. This is likely to cause the decision-maker to ignore certain information that might be important (George, 1974).

Miller (1960) hypothesized that people use three different strategies to handle time pressure. They are filtration, acceleration, and avoidance. When using the filtration strategy, the decision maker processes the important information first and then the other information in order of priority until time runs out. During acceleration, the decision maker processes the information at a faster rate which can lead to misinterpretation of the information (Miller, 1960). The decision-maker tries to avoid the situation during the avoidance strategy. These three strategies are very similar to Janis and Mann's coping patterns.

According to Edland and Svenson (1993) “decision rules are often characterized as compensatory or non-compensatory.” Using compensatory strategies, a poor evaluation on one aspect may be compensated by a positive evaluation on another aspect. When a “compensatory” decision is made, the alternative chosen is superior to the other alternatives when considering the sum of all the attributes, but is inferior to the other alternatives when taking into account the most important attribute. In non-compensatory, the value of an alternative is composed of the value of only some of its aspects. A “non-compensatory” decision is when the alternative chosen is superior to the other alternative only by virtue of the most important attribute to the decision maker and is inferior to the other when considering the sum of all the attributes. In an example of non-compensatory rule, alternative A can be chosen over B because A is superior to B in one favorable attribute, despite the fact that B is superior to A in all other attributes. The use of these rules was associated with different levels of information overload. Research suggests that subjects use more non-compensatory rules under high information overload (Edland & Svenson, 1993). Einhorn (1970) noted that non-compensatory strategies may be cognitively simpler and require the use of less information which indicates that non-compensatory rules could be easier and quicker to use under time pressure. Zakay (1985) investigated the relationships between time pressure and the type of decision process and found that the influence of time pressure decreased compensatory decisions. Post-experimental interviews indicated that under time pressure, the participants relied mainly on the information which they felt to be most important (Zakay, 1985).

Ben Zur and Breznitz (1981) investigated the effect of time pressure on risk-taking choices. They found that that when individuals were asked to make choices under high time pressure, they were more likely to choose a risky choice. Time pressure alone presents a stressful condition. Add to that the anxiety an individual feels when they are worried; sometimes a less

risky choice is often safer for them to make. When there is a comfortable amount of time to consider and evaluate information, cognitive strain and feels of inadequate performance decrease (Ben Zur & Breznitz, 1981).

Parents of Children with Hearing Loss

Many researchers and educators would agree that infants and toddlers with hearing loss should be identified as early as possible and provided with timely and appropriate audiologic, educational, and medical intervention. Recent studies have shown that children with hearing loss can achieve language abilities similar to hearing peers if intervention services are provided by six months (Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). According to The Joint Committee on Infant Hearing (JCIH), infants should be screened no later than one month old, have a comprehensive audiological evaluation by three months of age, and should receive appropriate audiologic and early intervention services no later than six months of age in order to maximize communication outcomes. Hearing aid selection and fitting should be provided by the audiologist in a timely fashion. Delay between confirmation of the hearing loss and amplification should be minimized to enhance outcomes in children with hearing loss (Joint Committee on Infant Hearing, 2007).

With the introduction of universal newborn hearing screening (UNHS), more children are being identified at a young age so parents must make decisions about audiology, communication options, and educational options very early in their child's life. As soon as the child is diagnosed with hearing loss the decision making process begins. After all that happens during the birth process, parents are typically physically and emotionally fatigued and are in no position to process crucial information especially if it is negative. We, as professionals, are asking the

parents to make these decisions under emotional stress which may mean their decision making ability is restricted.

Parents are obligated to face unfamiliar challenges while managing the disability early in the child's life and have to make very crucial decisions in a timely manner. Since there is large variability among children's outcomes with hearing loss, it is difficult to accurately predict outcomes for each individual child. Parents must make decisions without any guarantees of the future.

Also in the early stages of life, parents have to make frequent visits to audiologists and other professionals. These constant stresses may significantly drain parent's energy, time and financial resources, potentially leading to emotional reactions of frustration, depression, and social isolation (Quittner, 1991, p. 206-207). Anxiety, hopelessness, sadness, fear, and anger are only a few of the many emotions parents of children with hearing loss experience. Also children with hearing loss have communication difficulties that have a negative impact on the daily interactions between parents and their children who are deaf. This could lead to frustration and anxiety. In turn, these everyday interactions lead to increasing the parent stress level (Freeman, Dieterich, & Rak, 2002).

Rationale for Current Study

Receiving appropriate audiologic, educational, and medical intervention in a timely manner is crucial for the child's outcome. Research reveals that stress and time pressure negatively affect decisions, however, there is no research on this as it pertains to parents of children with hearing loss. This was the reason I conducted this study.

In my study, I had two very specific questions. First, I investigated to see if there were correlations between parental levels of stress and the time between receiving a diagnosis, getting

appropriate amplification, and early intervention. Second, I investigated the effect of time pressure parents experienced.

Methods

Procedure/Participants

IRB approval was received for my study in January 2012. In order to get answers to my questions, I sent one hundred surveys to parents with children who attended a private school in St. Louis, Missouri that emphasizes listening and spoken language for children with hearing impairments. The ages of the children were 8 months to 12 years of age. In January 2012, a detailed cover letter describing the survey, the participants' rights, contact information for queries, and procedures on how to submit their responses was attached to the survey and distributed to the families in the early intervention program, pre-kindergarten, and primary departments (See letter in Appendix A). The surveys were returned via a self addressed envelope that I provided. The families were asked to return the surveys by February 20, 2012. No personal identifiers were attached to the survey but date of birth was asked so age could be determined. Each survey was coded by a number and entered into a spreadsheet. Twenty one families returned completed surveys. See Table 1 for the ages of the participants' children.

Instruments

Although there are many ways to conduct surveys, I decided to use a written survey because not all families have access to the internet. This allowed for more families to participate. The survey took approximately fifteen minutes to complete. The participants were asked to rate their stress levels and feelings of time pressure on a Likert Scale with one representing no stress, five representing medium stress, and ten representing intense stress. The survey included some open ended questions for comments and thoughts. It also included some closed ended questions

that didn't require extensive responses (Survey in Appendix B). For the purpose of this study I refer to time pressure to mean feelings of being urged to do something as soon as possible or within a limited amount of time. Some surveys had missing information so the data reported varies in number.

Results/Discussion

Of the twenty one families that responded, eleven had children that referred on the newborn hearing screening. The average time between the newborn hearing screening and receiving a diagnosis was 8.3 months. The average stress rating after the newborn hearing screening was 5.9. See Table 2 for results. On a scale of one to ten, 5.9 indicates the families had relatively high stress levels after their child referred.

According to JCIH guidelines, infants who refer should receive follow-up testing no later than three months of age in order to maximize communication outcomes (Yoshinaga-Itano et al., 1998). Of the eleven families who referred at the UNHS, five (45%) did not receive a comprehensive evaluation by three months of age. This may be due to certain coping patterns during high stress levels. Defensive avoidance and hypervigilance coping patterns as identified by Janis and Mann (1976), state that the decision-maker avoids the conflict by procrastinating, shifting responsibility to someone else, or by creating wishful rationalizations and remaining inattentive to corrective information. Also, the decision-maker searches anxiously for a way out of the dilemma and grasps onto a fast solution that seems to promise immediate relief and overlooks the full range of consequences because of emotional excitement and repetitive thinking (Janis & Mann, 1976).

In order to gain more information, I asked families who referred at the UNHS, "*How were you counseled to follow up? What instructions were you given for follow up? Was it*

helpful?” Feedback was given by ten families. A list of the responses to these questions is as follows:

1. *After being referred, numerous appointments were made to follow up. We were told to make sure we followed up with audiologists and neurologists at the hospital.*
2. *People at the hospital tried to help us. We were told to go through First Steps and look through a folder of different options for services. It was overwhelming. There was a lot of information but the whole diagnosis was a lot to take in.*
3. *We received a letter from the hospital saying our child had yet to pass their hearing screening and we needed to get their hearing screening done as soon as possible. For their second screening, results were still inconclusive, so we were asked to set up an appointment for an ABR screening. We had no idea what an ABR screening was so when we called to set up an appointment, a woman explained to us about what would happen and what we needed to do before the screening. Letting you know about your child's hearing loss in a casual way was not helpful at all.*
4. *Follow up with an ENT and audiologist at the hospital. It was helpful but I wish there would have been more counseling or literature on the subject.*
5. *Get a test at the hospital. The instructions were helpful.*
6. *Get a repeat screening under sedation. They scheduled the follow up test prior to discharge of the hospital. The instructions were helpful. They told us the test procedure and what they would be able to tell us. The whole process was explained to us, even the things they didn't know were made aware to us and we had plenty of resources and support.*
7. *We were told to bring our child back for a second screening. Everything was vague, there wasn't much explanation about what refer meant.*
8. *Get an ABR at the hospital with a pediatrician. I thought the instructions were helpful at that time.*
9. *An appointment was made for another hearing test to be completed at three weeks of age. We were told to have our baby ready for a nap prior to testing and that the test would last a couple of hours. The instructions were helpful but I didn't know anything about the testing that would take place. I assumed it was the same test they had done at the hospital.*
10. *We were told to follow up with the hospital audiology and then we were referred to meet with three hearing schools in the St. Louis area and decide who was the best fit for our family. It was helpful, but still very overwhelming and unfamiliar.*

According to these responses, six participants revealed they felt directions were unclear and unfamiliar and they felt overwhelmed by the information. This could be a reason for their high stress ratings which in return may have prolonged the time to receive a diagnosis. Having

consistent, clear step by step instructions, as well as a more organized way of getting counseling and information to parents after the UNHS may ease their feelings of stress.

There may be other contributing factors to why five participants didn't receive a comprehensive evaluation by three months of age. One may be limited financial resources including no insurance. Some families may put off receiving a diagnosis due to the concern of being in a financial crisis. Families may be unaware of financial assistance and funding available to them. Another issue may be their child has other other medical factors that take precedence over the hearing loss. Also two families reported that their children were adopted. The adoption process may contribute to a longer time period between referral and diagnosis. These are just a few of the numerous possible contributing factors.

One recommendation for hospitals and pediatricians is to give a packet of information to families whose babies refer on the newborn hearing screening. The packet of information should consist of concise step by step instructions, information about the importance of receiving a diagnosis by three months of age, a description of how the Auditory Brainstem Response test is completed and what it can tell you, names of counselors, contact information for other parents with children who are deaf or hard of hearing, names of pediatric professionals, a list of early intervention providers etc. This would be a beneficial resource for the parents to have. It could help aide the parents in knowing what to expect and who to contact, especially for parents without access to the internet.

Out of the twenty one participants, twenty rated the process of getting a diagnosis as too fast, moved at a comfortable pace or didn't happen fast enough. Also, the participants were asked to rate the feeling of time pressure to follow up with additional testing at the time of the UNHS,

with one representing no time pressure, five representing medium time pressure, and ten representing intense time pressure. Table 3 displays the responses.

For the four participants that rated the process of getting a diagnosis as “happened too fast,” their average rating of time pressure to follow up was 1.3 which demonstrates a minimal feeling of time pressure. Three of the four participants provided a comment. Their comments were:

- *We were not expecting the diagnosis that our child had a hearing loss and it was very overwhelming while we were trying to understand what was going on. There was a lot of information that was being given to us about what to do next, when to do it, and it was too much for one day. The information was very important but we also needed a moment as a “new” family to cope.*
- *The audiologist made us feel it was no big deal. They didn’t give us any resources to help us understand.*
- *Because we didn’t expect a hearing loss the diagnosis was fast/sudden to us because it was out of the blue.*

These participants revealed they were unaware that a hearing impairment existed and felt the hearing loss diagnosis was sudden and unexpected. This may contribute to their rating the process as happening too fast because they were not ready to process the diagnosis of a hearing loss. Since these families didn’t expect their child to have a hearing loss, their rating of time pressure was very low (1.3) because they didn’t feel the urgency to receive a diagnosis since they didn’t expect anything to be wrong. Another reason for this could be that the child passed the UNHS thus creating a feeling that everything was fine. Perhaps a way to help these families is to give them a checklist of developmental milestones when leaving the hospital. If parents are made aware of the age appropriate milestones, they could be tracking this and notice sooner that their child was not meeting the milestones. Also, giving these families a packet of information when they receive the diagnosis would be beneficial. This would allow the families to look at the next steps when they are ready to process the information.

Eleven participants rated the process of getting a diagnosis as “moved at a comfortable pace.” Ben Zur and Breznitz (1980) found that when there is an adequate amount of time to consider and evaluate information, cognitive strain and feelings of inadequacy decrease. Perhaps these families had enough time after the newborn hearing screening to process the information and therefore felt the timing of everything happened at a comfortable rate.

Five participants rated the process of getting a diagnosis as “didn’t happen fast enough.” On a scale of one to ten, their average rating of time pressure to follow up with additional testing was 6.25. Their comments were:

- *We knew something wasn’t right but we were constantly being put off by medical staff!!*
- *I believed something was wrong for three months before anyone believed me.*
- *After the ABR I was told my child’s hearing was “normal” so all this time passed and really it was not normal. My child was 15 months and not saying mom/dad. At 18 months we found out our child didn’t have normal hearing. I was devastated! I felt too much time had passed.*

These families revealed they suspected something was wrong yet medical professionals didn’t “believe” them. This may contribute to their rating of the process as “not happening fast enough” because they felt too much time had passed. Because these families suspected something was wrong and time was crucial, this correlates with their high ratings (6.25) of time pressure. In order to prevent a delayed diagnosis, pediatricians and other medical professionals should be updated with current research on the importance of early identification. Also, parents should be able to request and receive a hearing test when they have concerns.

The time between the UNHS and the date of receiving amplification was calculated for the eleven participants whose children referred on the UNHS. The participants also rated their stress levels through the audiologic and amplification process. Table 4 displays the results.

According to JCIH, infants who refer should be fitted with amplification by the audiologist in a timely fashion. Delay between confirmation of the hearing loss and amplification should be minimized to enhance outcomes (Joint Committee on Infant Hearing, 2007).

According to my survey, the average time span from the UNHS to the fitting of amplification was 1 year 3 months. Only one participant had their child fitted with amplification within two months of the UNHS. These results do not coincide with JCIH recommendations. This long time period may be caused by the participants high stress levels. Their average stress level rating on a scale of one to ten was 7. Also, three of the four participants that had longest time span between UNHS and receiving amplification fitting rated their stress as intense. Research states the high intensity of stress is related to certain coping patterns. These families display qualities of ignoring the risk, procrastinating, and overlooking the full range of consequences. These are traits of unconflicted adherence, defensive avoidance or hypervigilance coping patterns (Janis & Mann, 1976).

There are other possible factors that could contribute to the delay. One factor could be the way information was given to the participants about the importance of amplification. The participants may not have known who to call to learn about the process of getting amplification. Also the participants may have tried to schedule appointments but the audiologist had limited availability. Another possible reason is the participants may have had transportation issues and getting to an audiologist was difficult. These are just a few of the possible contributing factors.

The time between the diagnosis and enrolling in an early intervention program and the age of the child when enrolled into early intervention was calculated for all twenty one participants. The participants were also asked to rate their stress levels when looking for appropriate services on a Likert scale from one to ten. This data is included in Table 5.

The participants average stress rating was 7.47, on a scale of one to ten. The average age of the child when enrolled in early intervention was 1 year 3 months. According to JCIH, children should receive appropriate intervention by six months of age (Joint Committee on Infant Hearing, 2007). This high average could be due to the fact that 10 participants had children that passed the newborn hearing screening. Only five participants had their child enrolled in Early Intervention by six months of age. The stress ratings of these five participants varied.

Even with the previous considerations, 1 year 3 months is 9 months later than recommended. This delay may account for the participants high stress levels. Fifteen of the twenty one participants rated their stress as high to intense when looking for services. This high stress could facilitate the avoidance coping pattern described by Janis and Mann (1976). As stated previously, providing families with a packet of information that includes a list of Early Intervention services and contact information may help lower families stress levels. Besides stress there are other possible contributing factors for this delay such as difficulty choosing the best Early Intervention placement for their family, fearful of financial cost, or had no access to transportation in order to enroll in services.

The 2007 JCIH Position Statement, reports that optimal intervention strategies for an infant with hearing loss requires that intervention must begin as soon as there is a confirmation of a hearing loss to enhance the child's acquisition of developmentally appropriate language skills (Joint Committee on Infant Hearing, 2007). For the participants in my study, the average time span between diagnosis of hearing loss to enrolling in early intervention was four months (see Table 5). This average is high due to participants 2, 11, and 17.

Ten of the twenty one participants (47%) enrolled their child in Early Intervention within one month of receiving a diagnosis. Of the ten participants that enrolled their child within one month

of receiving a diagnosis, eight participants followed JCIH guidelines and had their child enrolled by six months of age.

According to Table 5, after receiving a diagnosis, eleven of the twenty one participants (52%) took over one month to enroll their child into an early intervention program. Again high stress levels may contribute to this delay. Other factors could be that the participants lacked information on early intervention services, had no insurance, or were unaware of all the assistance programs such as Part C could offer their family. Even if the participants were given information, their stress could have caused them to not process things cognitively, which could add to the delay.

Twenty one participants were asked “ *Please rate your stress levels through the audiologic and amplification process*” and “ *at the time of diagnosis, what level of time pressure did you feel to get audiologic services, early intervention, and medical services in place*” One represents no pressure, five representing intermediate levels of pressure, and ten representing intense pressure. Also the participants were asked to rate the pace of getting audiologic, early intervention, and medical services in place as “moved too fast,” “ moved at a comfortable pace,” or “didn’t happen fast enough.” This data is displayed in Table 6.

According to the JCIH, hearing aid selection and fitting should be provided by the audiologist in a timely fashion. Delays between the confirmation of the hearing loss and the fitting of amplification should be minimized to enhance outcomes in children with hearing loss (Joint Committee on Infant Hearing, 2007). Eight of the twenty one participants (38%) had their child fitted with amplification within one month of receiving a diagnosis of hearing impairment which follows JCIH guidelines. Seven of the twenty one participants (33%) waited longer than two months after receiving a diagnosis to have their child fitted with amplification.

Participants C,G, L and O had the longest time between receiving a diagnosis and having their child fitted with amplification. These four participants' average time pressure rating was 7.75, on a scale of one to ten. This high feeling of time pressure may induce avoidance strategies described by Miller (1960). As stated earlier, when using the avoidance strategy, the decision maker avoids the situation in order to cope with the high ratings of time pressure.

As stated by Eihorn (1970) non-compensatory decisions are quicker and easier to use under time pressure. Edland and Svenson (1993) also state that non-compensatory decisions are more likely to be used when the decision maker is under high information overload. The participants that had a long delay may have demonstrated non-compensatory decision making by choosing not to receive a diagnosis because it was the easiest attribute. However, when considering all of the choices the participants could have made, they chose avoidance. Although this was the best option for them at the time, the other options could have led to better outcomes.

When comparing Tables 5 and 6, the participants high levels of stress and average time between receiving a diagnosis and enrolling in early intervention (4 months) as well as the average time between receiving a diagnosis and fitting with amplification (3.25 months), suggests the participants could have used the time pressure strategy, filtration, discussed by Miller (1960). During filtration the decision maker processes the important information first then the other information. The participants could have used this strategy by processing the diagnosis of the hearing loss first, then the process of being fit with amplification, and last enrolling in appropriate early intervention services. This could explain the data.

Eleven of the twenty one participants had children that eventually received cochlear implant(s). The participants were asked "*what level of time pressure did you feel to start the implant process?*" The participants rated their levels of time pressure on a Likert scale; one

representing no pressure, five representing a medium amount of pressure, and ten representing intense pressure. Also the eleven participants rated the process of getting a cochlear implant as: happened too fast, moved at a comfortable pace or didn't happen fast enough.

The eleven participants rating of time pressure to start the cochlear implant process was 5.18, representing a medium amount of time pressure. One explanation for this could be the participants felt time pressure to get a cochlear implant because their child wasn't getting enough benefit with hearing aids to assist in speech and language. Other reasons could be the participants wanted to mainstream their child faster or the child was getting because they were not getting enough information from their hearing aids.

One participant rated the pace of getting a cochlear implant as "happened too fast." This could be due to fear of the surgery, inadequate time to cope with the hearing loss, or were still getting used to hearing aids and weren't ready to switch to new devices. Eight participants rated the process as "comfortable," demonstrating there was adequate time to process the information and they were content with how the process moved. Two participants rated the process as "didn't happen fast enough." This could be due to delays in the process such as insurance or health complications. Because surgery is always a risk, this could cause a concern. Ben Zur and Breznitz (1980) investigated the effect of time pressure on risk-taking choices. They found that under high time pressure choices, participants were less risky. Since the majority of my participants rated the process as "comfortable" demonstrating risk taking, my results do not match their findings.

In order to gain information about the participant's support systems throughout their experiences, the participants were asked "*What/who was your biggest support throughout your experiences? Why?*" Twenty participants responded.

See responses below:

1. *Other parents, including parents online.*
2. *Upon receiving a diagnosis, all it took was one phone conversation with [staff member]. Our family could never repay all the friends we've made at [school name], for the support, and time they have provided us. Everyone from the custodians to the audiologists, from the nursery program to the pre-k . Everyone who works there plays a vital role in meeting [school name]'s mission. Truly we would not be where we are without everyone at [school name].*
3. *Initially it was the audiologist and then the therapists and then the teachers of the deaf. Everyone listened and heard us when we talked about our concerns. It seems to us that our biggest support was the people who were working with our child at whatever point in our journey. We gained a lot of knowledge and support from each one along the way.*
4. *All of the doctors and specialists that we have worked with have been great. Everyone was very educated in their field, although it was overwhelming in the beginning, it was also a lot easier to get things going in the right direction.*
5. *We truly did not have a support system throughout this time. We were too busy trying to figure out the next step.*
6. *[School name] stayed one step ahead at all times. [Staff Member] gave me every resource she could and helped further until my child was placed in school. She was great!*
7. *Everyone we have had contact with; the hospital, NICU staff, Audiology Department, Early Intervention and especially [school name] has answered all questions, called back, and scheduled appointments. I honestly have no complaints. I had no idea all the help I would receive with my child. I am quite impressed with the process.*
8. *The program my child was put in by [school name]. The help I received was a god send and [school name] helped me through it all.*
9. *Our Part C educator. She was the one who was able to explain things in a "down to earth" way and so it didn't go over our heads. Plus we feel very comfortable with her so it was easy to ask questions and give our true feelings.*
10. *[School name] teachers and staff were great. They were very knowledgeable and supportive.*
11. *Staff at [school name], online community and some family. They all gave support and information.*
12. *[School name]. After we had been trying to deal/learn about our child's hearing loss. They were the first to explain it to us so we understood what our child could hear/couldn't hear.*
13. *All members of [school name] were available and extremely helpful. However I used the family counselor on a very regular basis.*

14. *[School name] and the speech therapists because they were both very helpful and had answers to all my questions.*
15. *My spouse and the Part C program speech language pathologist.*
16. *My parent advisor from the state Outreach Program, [school name], and audiologists. They were caring and knowledgeable. Gaining knowledge was empowering. I really felt hopeless, but they were supportive and encouraging.*
17. *The service providers because they were there for us.*
18. *[School name]. They helped us throughout our stress and hardships in dealing with speech, physical therapy, audiology, and much more. They were the one who suggested a cochlear implant for my child. We have noticed a huge improvement in our child's speech.*
19. *My spouse and [school name]. [School name] has always made sure we knew what was going on and what was coming up. Also they make sure we are comfortable with everything.*
20. *My spouse, speech therapists, and my mother.*

Thirteen of the twenty responses stated that their school and other associated professionals were their biggest support. This may be due to the information, counseling, and support that the school provided. Two participants stated their spouse was one of their biggest supports. One participant stated they did not have a support system because they were too busy trying to figure out the next step.

“Family support is an important and yet often overlooked component. Although information is shared with the parents in many different ways, counseling is often in short supply (Sass-Lehrer, Mertens, & Meadow-Orlans, 2003).” A recommendation for families like this is to get them in contact with other parents of children who are deaf or hard of hearing. Perhaps talking with other parents will help ease their minds. Also giving them concise step by step instructions may help them understand the next steps so they are able to find support.

At the end of the survey, the participants were asked “*As we continue to learn more about how stress and time pressure affect decision making, do you have other thoughts or comments you would like to share?*” All the responses are listed below:

1. *There is so much information, new lingo, new people, etc. It's overwhelming and easy to make wrong turns or bury your head and do nothing. It's important to make connections with other families right away. I would love to see a list of mentor parents given to new families. Someone who says "I get it," may be a life line.*
2. *For us after the initial diagnosis, we just wanted to act quickly to help our child gain as much sound as possible so that she could develop speech and language. Both my husband and I were both sure right from the start that we wanted to be aggressive with her technology and therapy.*
3. *The first four years of our son's life has been very stressful on both my husband and I and our marriage. The situation was very unfamiliar to us and we had no idea what we were in for. Our biggest support ended up being the deaf educator we were assigned through [school name]. She helped us tremendously.*
4. *I feel that because I have a medical background, that I knew what questions to ask and that everything takes time. I do however feel that when it comes to your child anything but perfection is stressful. If a parent cares about the well being of their child there will be stress but there is lots of support to help them along. I appreciate all of the hard work that has gone into my child's care.*
5. *The stress is that others aren't aware and it makes more stress on the parent to keep up with and take care of equipment.*
6. *Thank goodness for Part C Program! Without it I'm not sure we would have known where to go or what to do. Also Children's Hospital helped set up most of the initial screenings and tests.*
7. *Reach out to other parents of children with hearing loss. The only way to truly know what to expect is to see it or experience it firsthand.*
8. *For us, we were very comfortable with the time of the whole process. We didn't feel too rushed that things weren't happening fast enough. Our biggest concern was the finances, right now we get assistance through early intervention but that won't last forever. Health insurance will not pay for anything with the hearing aids so we have to find a way to make it work. While there are support groups to help families cope with stress and help you understand everything, we have yet to find a group that will advocate for children with hearing loss and help fight insurance companies so that they become more responsible and cover some of the expenses with hearing loss.*
9. *Without [school name] I can't imagine what we would have done. They showed us a way and I'm so glad that they have always been there for my child. Today when I hear him talk, I can't thank them enough to get my child to this stage in his life. We are so thrilled to be a part of [school name] and have those wonderful teachers and staff. Thank you [school name].*
10. *My stress level was through the roof first finding out about his hearing. I then calmed somewhat until I found out the price of hearing aids. Then panic mode. I was very stressed when looking for assistance, that's when I found [school name]. Early*

intervention paid for the hearing aids. My child's hearing fluctuates and this was stressful because he would have some normal testings. Waiting for hearing aids to be placed I was more rested but anxious to see his reaction. I'm good with things now but time will tell.

- 11. I believe because my son was diagnosed so late, by the time I knew I was just relieved to have a diagnosis. I began searching for help immediately, but I believe I was already accepting of the fact that he was behind and understood the process would be slow no matter which route we took. However, I was frustrated over several doctors lackadaisical attitudes that perhaps his condition would just "fix itself" with a pair of hearing aids. I was given absolutely no direction by any doctor that treated him with the exception of a doctor that was referred by [school name].*
- 12. I have actually had to seek medical advice from my doctor because of stress related symptoms during this process and she thinks I have had some mild panic attacks-which are completely contrary to my natural personality. I think the stress and pressure are very real factors.*
- 13. I wasn't really stressed or felt time pressure as far as getting help and with the hearing aids. I felt more stressed and pressure to make sure I got it taken care of as quickly as possible for hopes she wasn't further behind in her learning.*
- 14. As a parent who wanted answers and help immediately for their child, I didn't think at the time things were moving fast enough. In hindsight, things were moving at a good pace.*
- 15. You can't control how/circumstances that parents find out their kids are deaf. But if parents would get more information in a timely manner.. referred to an audiologist that deals with pediatrics. Our lack of information or resources was stressful/upsetting.*

There were common responses to this question. The participants stated that not having enough materials or information for support was a stressor. Also fearing the financial impact of having a child with hearing loss was stated. It is imperative that parents receive more information about resources, support, and contact information early on in the process to support parents and help alleviate worries. Also the benefits of having other parents of children with hearing loss to talk to was constant theme. Parents that have been through the process can be a natural support. Giving parents step by step instructions and information about hearing loss as soon as their child refers on the UNHS can help make this process less stressful and more efficient. As previously recommended, hospitals and pediatricians should give packets of information to families

containing information on the importance of receiving a diagnosis by three months of age, resources for counseling, contact information for other parents with children who are deaf or hard of hearing, names of pediatric doctors, early intervention service providers, etc. Some parents may feel uncomfortable about asking for help however if names and contact information are given freely then possibly more parents would use this resource.

Another recommendation that was brought to my attention from a participant was the recommendation of starting an advocacy group that would help work with insurance companies to become more responsible to cover expenses or hearing technology. Perhaps this is something local politicians could help with.

Each family's situation is unique and there is no one factor that causes delays. However my study brought to light some important information. First, the participants in my study experienced high levels of stress and feelings of time pressure. These may be the cause of failure to meet JCIH guidelines. Second, the participants in my study revealed a crucial need for resources and information about hearing loss. If the parents had this information there could be an increase in meeting guidelines. Third, the participants declared they felt emotionally out of control and overwhelmed. Fourth, they did not receive enough information in the beginning to start the process. Finally, their school and other professionals helped them process the information and helped alleviate some stress and anxiety.

Additionally, completing this survey helped me to learn and understand that parents need better resources and an understanding of the importance of early identification. Knowing the possible causes for late identification and low parent participation, will help professionals working with families through the UNHS, diagnosis, and follow up services.

Practical Importance

It is important for professionals to be aware of the amount of stress parents have as well as understanding how stress affects decision making. Also it is crucial that professionals recognize the need for counseling and support services for parents as soon as possible to ensure healthy stress levels. Parents should be well educated on the importance of receiving a diagnosis and appropriate services in a timely manner as well as support in order for them to make the best decisions they can make. Also, keeping parents moving through the process with support in a timely manner would probably help them to meet JCIH guidelines and have better speech and language outcomes.

Limitations

Out of the many schools I could have surveyed, I only used one. This did decrease the amount of surveys returned. Because I didn't ask for specific information about the child and family, I am not sure the group would compare to a larger sample in terms of demographics. Also all the families surveyed were from the St. Louis area. It may be beneficial to survey families throughout the country to have a more accurate representation of what is happening in other parts of the country. Another limitation to this study is the vague definition of stress and time pressure levels. Using a better scale that was more detailed may help participants better rate their stress levels. Also I could have asked why the participants didn't move through the process faster. This would help determine specific causes of delay. Lastly, there is a lack of current research on stress, time pressure and decision making. Most of the resources used when writing this paper were thirty to fifty years old. Current research on the topic would help us to better understand the affect stress and time pressure has on decision making.

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Table 1

Ages of Participants' Children

Age	N=21
8 months-3.11 years old	12
4-7.11 years old	5
8-12 years old	4

Table 2

Stress levels of participants that had children with referrals at newborn hearing screening and the time it took to receive a diagnosis

Stress levels reported by participants after referring at UNHS	Time (months) between UNHS and receiving a diagnosis of hearing loss
10	3
10	1
10	18
8	8
8	2
5	1
5	25
5	4
2	3
1	26
1	1
Average= 5.9	Average= 8.3

Table 3

Rating of the pace of getting a diagnosis and rating of time pressure to follow up from screening to diagnosis

Rating	N= 20	Time pressure to follow up from screening to diagnosis
<i>Happened too fast</i>	<i>4</i>	<i>Average= 1.3</i>
<i>Moved at a comfortable pace</i>	<i>11</i>	<i>Average= 5.18</i>
<i>Did not happen fast enough</i>	<i>5</i>	<i>Average= 6.25</i>

Table 4

Stress levels reported by participants that had children with referral at UNHS throughout the audiologic and amplification process and the time it took to get the child fitted with amplification

Stress levels reported by participants throughout the audiologic and amplification process	Time between UNHS and fitting the child with amplification
10	1 year 10 months
10	2 years 2 months
10	2 years 1 month
9	7 months
8	2 months
8	5 months
6	5 months
5	9 months
5	2 years 2 months
4	No Response
2	5 months
Average: 7	Average: 1 year 3 months

Table 5

Participant's stress rating when looking for services, the amount of time between diagnosis and enrolling in Early Intervention, and the age of the child when enrolled in Early Intervention

Family	Participant's stress rating when looking for services	Time (months) between diagnosis and enrolling in Early Intervention	Age of child when enrolled in Early Intervention
1	10	5	3 years 9 months
2	10	22	2 years
3	10	2	5 months
4	10	1	9 months
5	10	6	1 year 10 months
6	10	2	1 year 10 months
7	10	5	2 years 7 months
8	10	1	4 months
9	9	0	1 year 11 months
10	8	1	1 month
11	8	23	2 years 2 months
12	7	0	1 year 7 months
13	7	2	1 year 10 months
14	7	0	2 months
15	5	0	1 month
16	5	0	1 month
17	5	11	1 year
18	5	0	4 months
19	4	0	1 year 1 month
20	4	2	2 years 3 months
21	3	1	1 year 2 months
Average= 7.47		Average= 4 months	Average= 1 year 3 months

Table 6

Participant's rating of time pressure to get services, time between diagnosis and child fitted with amplification, and description of the pace of getting services

Family	Parents rating of time pressure to get audiologic services, early intervention and medical services in place	Time (months) between diagnosis and child fitted with amplification	Description of the pace of getting audiologic, early intervention, and medical services in place
A	10	1	Comfortable
B	10	2	Comfortable
C	10	20	Comfortable
D	10	0	Comfortable
E	10	2	Comfortable
F	10	1	Comfortable
G	9	6	Too Fast
H	8	2	Not Fast Enough
I	8	2	Too Fast
J	8	1	Too Fast
K	7	3	Comfortable
L	7	7	Comfortable
M	6	NA	Comfortable
N	5	2	Not Fast Enough
O	5	7	Comfortable
P	5	3	Comfortable
Q	4	1	Comfortable
R	4	2	Comfortable
S	4	1	Comfortable
T	2	1	Not Fast Enough
U	1	1	NA
Average= 6.81			Average= 3.25
			3= Happened Too Fast 14=Comfortable Pace 3= Didn't Happen Fast Enough

Appendix A

Letter to Participants

Dear Parents,

My name is Lindsey Schutte and I am a graduate student in the Program in Audiology and Communication Sciences (PACS) at Washington University School of Medicine. I am a second year deaf education student and I am currently working on a research study as a requirement for my graduation in May.

I'm interested in how time pressure and stress affect parents' decision making abilities regarding hearing loss and devices such as hearing aids and cochlear implants. There appears to be very little research on this topic. If you agree to participate, please complete and return the enclosed survey in the stamped envelope provided. The survey will take about 15 minutes.

There are no risks and no benefits to participating. There are no costs for participating and you will not be paid. Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as federal government regulatory agencies, University representatives, to complete University responsibilities and/or Washington University's Institutional Review Board (a committee that reviews and approves research studies) may become aware of your participation in this study and may inspect and copy records

pertaining to this research. Some of these records could contain information that personally identifies you.

To help protect your confidentiality, the survey does not contain any names. Once surveys are returned to the PI, data will be entered into a spreadsheet and the surveys will be shredded. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

If you wish to participate, please return the completed survey in the self-addressed, stamped envelope by February 20, 2012. If after receiving this letter, you have any questions about this study please feel free to contact me at schuttel@wusm.wustl.edu or my independent study advisor Chris Clark at cclark@cid.edu. If you have questions about the rights of research participants, please contact the Human Research Protection Office, 660 S. Euclid Ave., Campus Box 8089, Washington University St. Louis, Saint Louis, MO 63110, (314) 633-7400, or 1-(800)-438-0445 or e-mail hrpo@wusm.wustl.edu.

Thank you very much for your consideration.

Lindsey Schutte

Appendix B

Survey

Hearing History

When was your child born?

Month _____ Year _____

Did your child receive a newborn hearing screening? ____yes ____no

What was the date of the newborn hearing screening?

Month _____ Year _____

What were the results of the newborn hearing screening? (pass or refer)

Left _____ Right _____

What was the date of your child's diagnosis? (Please complete even if your child wasn't screened at birth).

Month _____ Year _____

Does your child wear hearing aid(s)? ____yes ____no

What was the date your child was first fit with hearing aids? (Please complete even if your child wore hearing aids prior to receiving a cochlear implant).

Right Ear: Month _____ Year _____

Left Ear: Month _____ Year _____

Does your child wear a cochlear implant (CI)? ____yes ____no

What date did your child have cochlear implant surgery?

Right Ear: Month _____ Year _____

Left Ear: Month _____ Year _____

What was the month and year your family enrolled in early intervention?

Month _____ Year _____

If your child referred on the Newborn Hearing Screening, how were you counseled to follow up?

What instructions were you given for follow up?

Were the instructions helpful? What wasn't helpful?

Additional Comments:

Please read: *Many researchers and educators would agree that infants and toddlers with hearing loss should be identified as early as possible and provided with timely and appropriate audiologic, educational, and medical intervention.*

Considering the statement above:

Please rate your stress levels after Newborn Hearing Screening:

1	2	3	4	5	6	7	8	9	10
No Stress			Medium				Intense Stress		

Please rate your stress levels after your child received a diagnosis:

1	2	3	4	5	6	7	8	9	10
No Stress			Medium				Intense Stress		

Please rate your stress levels when you were looking for appropriate services:

1	2	3	4	5	6	7	8	9	10
No Stress			Medium				Intense Stress		

Please rate your stress levels through the audiologic and amplification process:

1	2	3	4	5	6	7	8	9	10
No stress			Medium				Intense Stress		

There are individual differences in how people react to time pressure.

Considering the above statement:

At the time of Newborn Hearing Screening, did you feel time pressure to follow up with additional testing?

1	2	3	4	5	6	7	8	9	10
No Pressure			Some Pressure				Intense Pressure		

Did the process of getting the diagnosis_____. (choose one)

_____ Happen too fast

_____ Happen at a comfortable pace

_____ Not happen fast enough

Additional Comments:

At the time of diagnosis, what level of time pressure did you feel to get audiologic services, early intervention, and medical services in place?

1	2	3	4	5	6	7	8	9	10
No Pressure			Some Pressure				Intense Pressure		

Did the process of getting audiologic services, early intervention, and medical services _____. (choose one)

- _____ Happen too fast
- _____ Was at a comfortable pace
- _____ Did not happen fast enough

If your child received a cochlear implant(s):

What level of time pressure did you feel to start the cochlear implant process?

1	2	3	4	5	6	7	8	9	10
No pressure			Some Pressure				Intense Pressure		

Did the process of getting the cochlear implant:

- _____ Happen too fast
- _____ Move at a comfortable pace
- _____ Did not happen fast enough

What/who was your biggest support throughout your experiences? Why?

Comments:

As we continue to learn more about how stress and time pressure affect decision making, do you have other thoughts or comments you would like to share?

[illegible]